

LOCAL & STATE, B1

Maine caught up in 'grinding' debate

HOME & FAMILY, E1

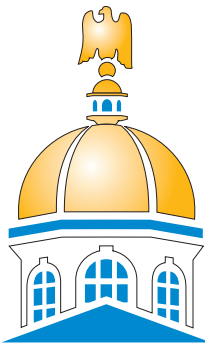
A trip to a 'green' Vermont B&B



SPORTS, C1

Catching up with Matt Bonner

SUNDAY



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Carolynne St. Pierre explains to her son, Elijah, 4, that she has to be gone for a few days. Her husband, Rich, rushes around the house to get ready. Carolynne must travel to Brooklyn, N.Y., to receive experimental chemotherapy treatments. **Below:** Family and friends signed the border of Rich and Carolynne's wedding photo.

remember me

Carolynne St. Pierre endures exhausting cancer treatments for one reason: so her kids will know who she was when she's gone.

By CHELSEA CONABOY
Monitor staff

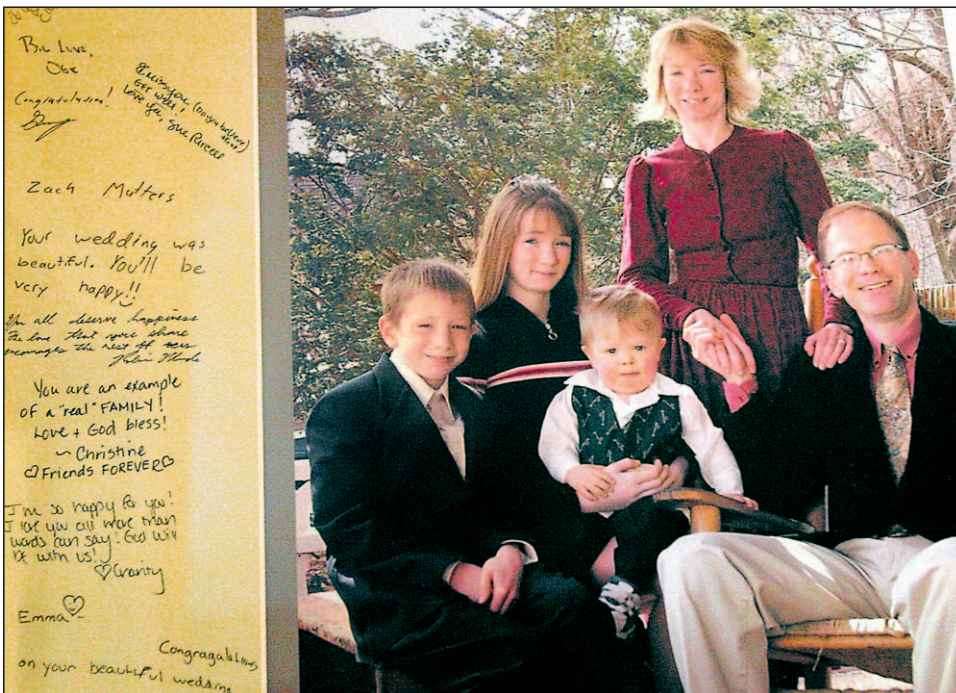
Each time 44-year-old Carolynne St. Pierre comes home from chemotherapy at Brooklyn's Lutheran Medical Center, fatigued and sometimes nauseous, she talks about putting off the next treatment.

The hospital is difficult to get to. Sometimes she takes a bus from Concord to Boston, then a train to New York City and a subway downtown to her mother's apartment, so tired by the end that she can barely carry her suitcase up the stairs to the street. Other times, her husband, Rich, drives her to Connecticut, where one of her sisters picks her up. Then he rushes back to care for their three kids.

The experimental treatments are expensive, about \$16,000 a visit, and the St. Pierres aren't sure yet what insurance will cover. They fear it won't be much. And then there's the fact that the drugs likely won't save Carolynne's life.

What they may give her, and what keeps her going back, is more time.

Time to spend with 14-year-old Melissa, 12-year-old Brian and 4-year-old Elijah, making memories that she hopes will last long past the day when chemotherapy no longer can keep her cancer in check, the day when she



See REMEMBER - A6

NORTH KOREA SANCTIONS PASSED

The U.N. Security Council voted unanimously yesterday to impose sanctions on North Korea, following the country's suspected testing of a nuclear weapon.

North Korea's ambassador to the U.N. said "If the United States increases

pressure upon (North Korea) persistently, (it) will continue to take physical countermeasures, considering it as a declaration of war."

The sanctions were passed after China and Russia raised objections to the original U.S. plan.

Story, A2

Silver Star awarded to modest guardsman

Ghent went after insurgents with pistol

By JOELLE FARRELL
Monitor staff

Soldiers practice for war. But no one knows how he or she will react when the battle is real.

When that moment came for Spc. Richard Ghent in March, he'd been blown out of a Humvee and

was lying on the ground in Ramadi. The driver of the Humvee was dead and the staff sergeant in the passenger seat was badly injured and unconscious.

Ghent was wounded, but he didn't wait for help. He grabbed the only weapon on him - a 9 mm pistol - and chased after the insurgents who'd attacked his vehicle.

Yesterday, Ghent, 21, of Rochester, was awarded a Silver Star for bravery. The award is the

third highest given for valor in enemy fire; Ghent is the first New Hampshire National Guardsman to receive the honor since the war on terror began.

Ghent says he was just doing his job. He seemed almost embarrassed by the attention he received at the ceremony, held yesterday afternoon in the drill shed of the National Guard Armory in Man-

See MEDAL - A12

Who will care for seniors?

As guardians help, exploitation is feared

By MEG HECKMAN
Monitor staff

It's increasingly difficult for New Hampshire's judges to find guardians for seniors who are too ill to make decisions about their health care and finances.

As a result, courts are relying for the first time on private businesses that profit from supervising frail elders. These guardians can pay bills, make medical decisions and decide where the senior lives. Sometimes they referee family disputes or untangle decades of messy bookkeeping. Often, they serve as guides through the medical, financial and emotional complexities of aging.

"When you have an outside guardian, you can go about the business of being a family, and let me take care of all the junk," said Jeannette Marino, a guardian from Concord. "I'm not there to tell you what to do. I'm your customer representative. What do you want me to do?"

Judges, state health officials and guardians like Marino say services like these are meeting a fast-growing need, but fear that, without strict supervision, some guardians-for-hire might exploit their wards. Courts review guardianship cases annually but often work with limited information. Mary McGuire, legal coordinator for the state's Bureau of Elderly and Adult Services, says this creates the potential for abuse.

"Courts can only make decisions based on the information they have," she said. "If it's the guardian providing the court with the information, they're going to cover up if they're doing something inappropriate."

She's working with the courts to devise uniform guidelines to prevent problems as demand for guardians' services increases.

Guardians wanted

Between 2002 and 2005, guardianship requests at the state's 10 probate courts rose 20 percent, from 760 to more than 900. Usually, a friend or family member assumed responsibility, but that wasn't always possible. In several cases, incapacitated seniors waited for days in the hospital while the courts searched for someone willing to approve their transfer to a nursing home.

"We need a guardian, and we don't have anyone to serve in that capacity," said Judge John Maher, administrator of the state's probate courts. "I've been a judge now for 23 years, and this is the first time" there's been a shortage.

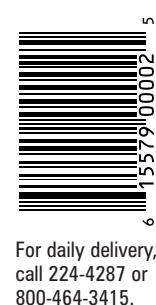
A little more than a year ago,

See GUARDIANS - A12



OKAY: Sun, clear tonight. High 58, low 26. Samuel Marquis, 9, of Gilmanton Ironworks draws the day. B6

Books	D4
Business	F1
Classified	G2
Editorial	D1
Home & Family	E1
Local & State	B1
Obituaries	B2
Sports	C1
Travel	D6
Tuned In	F6



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Four-year-old EJ hugs his mom as he and Rich say goodbye at the bus station in Concord before sending Carolynne for a chemotherapy treatment in New York.

“It’s okay to go through this together”

will die. Time for Rich and Carolynne to find ways for Carolynne’s influence – her soft touch and motherly advice – to remain after she’s gone.

For the St. Pierres, there is a constant balance of preparation and hope. They talk to the children about their mother’s prognosis, discuss what her funeral will be like and cry together. But Carolynne also sets goals, always sets benchmarks in her children’s lives, and celebrates when she reaches them.

First, it was to make it to the first day of school. Now, Halloween. Next, Christmas and the new year. Later it will be another summer to sit on the beach while little EJ plays in the water.

“A total dream of mine would be seeing Melissa’s 16th birthday,” she said.

Without effective treatment, doctors have said, Carolynne’s health would start to fail quickly in about two to four months. Carolynne sometimes doubts whether she would be getting the treatment if all she had to worry about was her own health. She dreads the thought of chemotherapy dragging on for years. But she hopes, with Rich’s encouragement, for as much time as she can get. Especially for EJ.

Rich’s mother died when he was 7. He doesn’t remember her and, because she died suddenly, she left no notes or remembrances for him to hold onto. While he thinks their mother’s death will be hard for Melissa and Brian (whose last name is Thone and who are from Carolynne’s first marriage), he worries most that EJ St. Pierre, a rough-and-tumble boy who clings to his mother, won’t even have a faint imprint of his mother in his mind as he grows.

“Without Carolynne, I don’t let myself go there very often, but it’s going to be really hard,” he said. “I know that.”

Carolynne shares his fear.

“The thought that EJ wouldn’t remember me – wouldn’t even remember me –” she said.

Rich knows all three kids will crave stories about their mother when she is gone. So he and Carolynne look for ways to preserve them now. Inviting the *Monitor* to follow them for the past six months was one of them.

Courting Carolynne

There’s a knowing desperation in the way Rich, who is 44, works around Carolynne’s illness, waking at their Second Street home most days before the sun is up, grocery shopping and running errands before the kids are off to school and day care, and often running his geo-spatial surveying business from home to be with Carolynne and to make calls to doctors and the insurance company. Then he picks up Melissa from gymnastics, Brian from football practice, and works until the sun goes down again and the rest of the family is asleep.

Add to that business trips and doctors’ appointments. During the

busiest weeks, time to pray and exercise, the things that help him stay grounded, is lost.

Just as Carolynne talks about her cancer as “a family illness,” Rich seems to absorb it. The days before her diagnosis were days when “we were healthy.” After some difficult treatments, he said, “we’ve lost a lot of weight.”

“Sometimes we get chilly,” he said as he handed a blanket to Carolynne, a petite woman made to look smaller by layers of clothing, often pink and fleecy.

Their loyalty wouldn’t be surprising to find in a couple in their golden years. But the St. Pierres’ love is relatively young.

They met on a blind date in 2000, set up by a friend of Rich’s whose baby was being cared for at Concord Hospital’s maternity ward, The Family Place, where Carolynne – then Carolynne Seigle – was a nurse. She hadn’t dated anyone since her divorce a few years earlier, and it wasn’t until after much hassling from co-workers that she agreed to the setup.

As a single mother, she juggled three babysitters to cover her 12-hour shifts. The babies she cared for were her passion. Her work – where she was known for her bouncy, blonde ponytail, ever-present wit and generosity of time toward new mothers and new nurses – was her



Rich cleans up after EJ had an accident in his pants. Though EJ had been potty trained for months, he regressed when Carolynne had to spend a few days in the hospital this summer.



Carolynne waves while watching EJ play at the beach on New Castle Island. Summer family trips inspired Carolynne to continue with her chemotherapy in hopes of being around next year. She sets short-term goals to help her make it through exhausting treatments.

social life.

On April 15, Rich, who had never been married, took her in his new Passat to Portsmouth, to a play, dinner and a walk on the beach.

“It felt like being a teenager, out getting away with something,” she said.

Their relationship grew quickly. For her, Rich was the opposite of her first husband.

“He’s so even keeled,” she said. “He’s spiritual. He’s dependable.”

Rich was drawn to Carolynne’s softness and her dedication to nursing. She introduced him to what it was like to have children. He helped her reconnect with family members in New York and New Jersey, particularly her two sisters, from whom she’d grown apart during her first marriage.

Just before Thanksgiving 2001, Rich and Carolynne stood together in the bathroom of her Concord home with a pregnancy test in hand. Outside, a car was packed for a long weekend at her sister’s house, and the kids were ready to go. The couple had only talked about getting married and hadn’t intended on having children. The test was positive.

“We were in shock,” Carolynne said.

At first, Rich was anxious about how a baby would change things. “Finally I was like, you know, this is totally good,” he said.

“Plus, I was in love with you,” he said to Carolynne as they recounted the story. “So, it didn’t matter.”

‘In sickness and in health’

In December 2001, Rich proposed and moved in with Carolynne and the two kids. Elijah was born in July.

After not having a mother in his life, Rich found a lot of joy first from hearing Carolynne’s stories about babies at work and then watching her as a mother to EJ. “For me, there was a completeness,” he said.

He and Carolynne talked about a wedding, but everyday life got in the way.

In the summer of 2003, when Elijah was nearly 1, Carolynne started having pain in her chest and right shoulder. Doctors told her it was likely from the way she held her son, and they prescribed physical therapy and anti-inflammatory medication. They gave her a chest X-ray and, when the pain got worse, an EKG.

Months passed and the doctors couldn’t find anything wrong. In November, one suggested she try anxiety medication. She came home frustrated. She thought the doctor didn’t believe her.

“You know your own body, and you know how you feel,” she said. “And I knew something wasn’t right.”

In January 2004, she developed a chronic cough. When a doctor suggested she try an inhaler, she pushed to see a pulmonologist.

A March CT scan found nothing wrong with her lungs. But, by chance, the pulmonologist spotted something on her liver that worried

him. He referred her to a specialist at Massachusetts General Hospital. Carolynne felt relieved: After nine months of doctors' appointments, finally she was getting some answers.

But on April 8, 2004, Rich and Carolynne stood in the hospital courtyard crying. The doctor had just told them Carolynne had cholangiocarcinoma, a rare cancer of the bile ducts of the liver. She'd later learn that a condition that she had been treated for since 1995 called primary sclerosing cholangitis, an inflammation of the liver, is thought to be a precursor. Carolynne doesn't remember doctors ever telling her to worry about cancer.

Carolynne would have to have surgery to remove a large tumor from her liver. A surgeon at Massachusetts General told her she was "short on time" and advised her not to shop around for doctors, the St. Pierres said. He also said the surgery was risky, and, if it got too complicated, he would close her up. The St. Pierres scheduled the procedure for April 27 and shopped anyway.

"We weren't willing to accept a bleak outcome," Rich said.

They flew to New York, where Carolynne's aunt, Caroline Stoessinger, had connections at the best hospitals. They saw specialists at Memorial Sloan-Kettering Cancer Center and Mount Sinai Hospital. At each visit, Rich collected business cards and took meticulous notes.

One doctor said he would operate. Another refused. Stoessinger pressured one, asking whom he would send his daughter to. He told them Roger Jenkins, a liver transplant specialist at the Lahey Clinic in Burlington, Mass. They went to see him right away and found what they were looking for.

"He didn't guarantee us anything, but he held Carolynne's hand," Rich said.

Jenkins would keep the April 27 date. Meanwhile, the St. Pierres got the family's business in order. They arranged Carolynne's power of attorney and her will, which included her wishes for Rich to have legal guardianship over Melissa and Brian.

Friends and family pulled together an impromptu wedding. They cooked a wedding feast, complete with two cakes. A nursing friend lent Carolynne her wedding dress. They rented a tent to put up in the backyard, where the Rev. David Jones of St. Paul's Church oversaw the ceremony and the couple struggled to say their vows.



Rich comforts Carolynne before a recent CT scan at Concord Hospital. "Carolynne's been beating the odds," he said. "They all are genuinely surprised that Carolynne's still alive."



Brian, 12, hugs his mom and Melissa, 14, tries to block Rich's view as he takes a picture with his cell phone. Carolynne wanted to be there for Melissa's first day at Concord High School.



Rich takes a photo of Carolynne after they both had their heads shaved. Carolynne's friend, Ellie Duhaime (right), who was there for support, checks the makeup she just applied to Carolynne. Barber Lindsay Clukay (back) made a house call for the couple.

"In sickness and in health... It was so real," Carolynne said.

Accepting the diagnosis

Three days after the wedding, Carolynne was prepped for surgery. On the drive to the Lahey Clinic, she and Rich made a list of things she wanted for the kids: counseling, to be surrounded by friends, to go to college, to stay involved in sports and music, to spend summers in New York with her family.

The surgery lasted 11 hours; Jenkins removed about 35 percent of her liver.

Carolynne spent the next six months in and out of the hospital, and for much of that time was tethered to feeding tubes. Because she was struggling to get stable, she couldn't start chemotherapy. Rich sold his prized Harley-Davidson motorcycle and later his New Hampton home to help cover medical costs. Plans to send the kids to private school were pushed aside.

In the beginning, Carolynne asked people not to use the word "cancer" around her. When she was given books about coping with illness, she'd turn the bindings to the wall.

"If I didn't really soak it in, if I didn't really admit it, it wouldn't be happening," she said.

But friends and family knew what was happening and knew the St. Pierres needed help. They brought plates of food, so plentiful that the St. Pierres bought an extra freezer. Carolynne's mom, Kathryn Seigle, and other family members helped around the house. Anonymous checks and cards arrived in the mail by the dozen, and friends shuttled the kids to school, day care and extracurricular activities. Nurses at The Family Place made Carolynne a patchwork baby blanket.

Slowly, Carolynne's pain subsided, and she regained strength. The family enjoyed Christmas 2004 together. In January, Carolynne had a CT scan that showed no signs of recurrence. That month was "euphoric," Rich said.

Three months later there was another tumor. It was time for chemotherapy. Carolynne had to tell her nursing supervisor that she would not be coming back to work.

The St. Pierres worked as hard to find an oncologist as they did to find a surgeon, visiting various hospitals and asking the doctors the same question: Where would they send their own families?

They settled on Dr. Howard Bruckner at Lutheran, the former head of the gastrointestinal oncology

See **REMEMBER - A8**



Carolynne watches EJ play in the window while Rich is gone on a business trip. Carolynne says she worries about taking EJ outside alone because she no longer has the energy to keep up with him.

Photos by Preston Gannaway Story by Chelsea Conaboy

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REMEMBER

Continued from A7

gy section at Mount Sinai Hospital, where he had worked for 30 years. What they found in him was hope. Where some doctors told Carolynne that she should enjoy the months she had left with her children, Bruckner said he would try to help.

Bruckner, who sees hundreds of patients, bucks the trend in oncology of using fewer drugs in maximum doses. He believes partnering drugs in smaller doses can increase their effectiveness.

"Occasionally, the results have been very, very dramatic," he said.

Bruckner said many doctors rightly avoid giving patients chemotherapy that's unproven by standard measures because they worry that the drugs will do more harm than good. But Carolynne's cancer is an "orphan" disease, with only about 2,500 people diagnosed in the United States each year. As a result, there isn't much government support for costly trials.

Cholangiocarcinoma is aggressive, and Carolynne's tumor is particularly invasive, he said. "She's in that category of someone where the evidence-based choices are not thrilling."

For three months, Carolynne traveled to Brooklyn every two weeks. During that time, the St. Pierres received word that Carolynne's insurance company, Cigna, wouldn't pay. The objection was not to the treatment but to the fact that Brooklyn was out of geographical coverage range. The St. Pierres filed an appeal, and the company said it would cover one round of chemotherapy in Brooklyn, then Carolynne had to find a doctor in New England.

Dr. Fred Briccetti at New Hampshire Oncology agreed to administer the blend of drugs in Concord. Between treatments last fall, Carolynne went to Melissa's cheer-leading practices and Brian's football games.

"I cried every time, because all I could think about in my head is, 'I'm here this year, but will I be here next year?'"

As the months passed, she became frustrated at not being able to do the things she once did. She spent a lot of time at home, reading and watching television. The change was difficult for the kids, too.

"Cancer almost sucked most of the life out of her," Melissa said.

Brian said his mom's health seemed to ping-pong. One day, she'd be fine. "Then, it's like Dr. Hyde gives her a potion and she's sick," he said. The uncertainty was unnerving.

Rich and Carolynne started preparing for the days when her health would worsen still. They set up binders for each of the kids' medical records and added history that only Carolynne knew. She picked a kindergarten teacher for EJ and directed Rich to enroll him in swimming lessons and take him on an annual trip to Story Land until he's outgrown it, as she had done with the older kids.

Back to Brooklyn

One morning last April, Carolynne woke up and watched EJ sleeping next to her. He opened his eyes, put his arm around her and said, "Don't go anywhere, Mom."

Earlier in the month, she had received news that her cancer was advancing. Bruckner wanted to intensify Carolynne's treatment, adding a drug called Avastin, which he said can make other drugs more effective by making cancer cells less resistant. While Avastin is approved for use against colon cancer, it is not approved for cholangiocarcinoma.

That extrapolation - saying what works for one kind of cancer could work for another - was something Briccetti in Concord was uncomfortable with.

So the St. Pierres went back to Brooklyn and back to fighting with the insurance company, which now rejected the treatment based on its experimental status.

The new treatment was harder on Carolynne's body. She took more time to recover. She lost her appetite and limited her driving.

It became harder for her to care for EJ on her own. He's a sturdy boy who likes running circles around the living room, climbing on furniture and pouncing from couch to couch. Carolynne became afraid to take him outside the house on her own, worried that he'd run off toward the Merrimack River nearby and she wouldn't be able to chase him.

She thought about whether to continue treatment. But the doctors said she was doing better than expected. And "the alternative right now is so scary and so sad," she said.

Melissa said it wasn't until this year that she realized how serious her mom's cancer was.

"You know something's happening, but you haven't really thought it through all the way," she said.

The St. Pierres said they've been frustrated by the lack of group counseling services in the Concord area for children of parents with cancer. They've tried to keep the kids in their normal routines while also telling them all that they can about the cancer. They've explained Carolynne's treatment and that, one day,



Carolynne's mother, Kathryn Seigle, kisses her as the family gathers around for Carolynne's 44th birthday in August.

it will no longer work. Still, Rich said, he worries that they don't understand that their mother will die.

"You hurt for a long time when you lose a parent as a child," he said. "If they know what it is, it's going to make it easier for them."

Melissa said his constant reminders are frustrating. More recently, as she's had to do more around the house, giving EJ his nightly baths and cooking dinner, she said it has started to "click in" that things will be different without her mom.

But, she said, she thinks of herself as just another Concord High School freshman, going to class and gymnastics practices, doing her homework and spending time with her friends.

Brian's reaction is different. He gets angry and acts out, sometimes posing a discipline challenge for Rich and Carolynne. "Look around, smell the coffee," he said last spring. "This isn't really normal for anyone."

He said he can't help but get angry sometimes at not having a healthy mom to take care of him.

"Our bodies react to the environment of what's happening," he said. "When something's wrong, I can feel it in my blood."

It's hard for the St. Pierres to gauge how EJ is coping. Over the summer, he regressed in potty training. When his mom is not around, he looks for her. And when Carolynne leaves for treatment and explains that she'll be home soon, he tells her she's "not coming back."

Carolynne doesn't worry about Rich raising him well. But she worries about EJ not having a mother's influence. That EJ is a boy is helpful. Rich doesn't have much experience with girls. Luckily, Melissa is low maintenance, Carolynne said, as she and Melissa sat in the living

room on Mothers Day between dinner and cake.

Rich poked his head out of the kitchen and smiled at Melissa.

"We'll manage," he said. She returned a teenage smirk.

'Still lots of value'

At the end of May, a CT scan showed no new tumor growth. That was good news, but the St. Pierres had been questioning how often Carolynne should go to treatment, and the results made for difficult decision making.

"You're making believers out of our local oncologists," Rich told Bruckner during a conference call. "They still won't do the plan, but they scratch their heads."

The St. Pierres scheduled another treatment for the first week in June. Shortly after Carolynne returned, she ended up in the hospital with a fever and a low count of white blood cells. The hospitalization, though just a couple of days, made her question whether to go again.

"If it meant that every time I went for a treatment and came back home, it meant that I would end up in here for time to recover, it wouldn't really make sense to keep doing it," she said from her hospital bed.

Ten days later, she prepared for another trip to Brooklyn. In the morning Rich shaved her head, and the Rev. Jones stopped by for a visit. Carolynne talked about her fears of dying and of how her death would affect her family.

"Rich has been through enough in his lifetime," she said. "We don't want Elijah to lose his mother. And then I feel bad for Melissa and Brian that they have to have this kind of stress in their lives. . . . It hurts me that it's something I don't have control of that potentially

could make my family really sad."

Rich is more forgiving of God and their situation.

"It's not okay to be sick, but it's okay to go through this together," he said. "I wouldn't have it any other way."

When Carolynne returned from treatment, she talked more than ever about postponing the next one. She wanted to feel well for an Adirondack vacation they'd been planning for the end of July. But putting it off would mean going at least five weeks without treatment.

"It's a crapshoot," Rich said. "It's hard to know what you lose if you don't do a treatment."

Carolynne's siblings and mother always prod her to go. "I want to keep her," Kathryn Seigle said.

Carolynne scheduled a treatment for mid-July. In the week leading up to it, she and Rich took EJ and Melissa to Story Land and twice brought EJ to the beach. The day trips boosted Carolynne's determination to get to another summer to watch her son play in the water.

The night before she was supposed to leave for treatment, Carolynne had a 103-degree fever and had to postpone, moving chemotherapy a few days closer to vacation. By the time she got home, she was nauseous and couldn't eat. She had sores in her mouth and down her throat and pain in her shoulder.

The St. Pierres first delayed the vacation, then canceled it. Carolynne was downtrodden.

August brought Carolynne's 44th birthday, another treatment and preparation for the first day of school, which was filled with normal sibling banter when it came.

"Brian, if you're not nice, I'm not giving you rides when I'm a senior and you're a freshman," Melissa

said as the two put their shoes on and collected their bags.

"It's not like you're going to get some Miata," Brian said. "You're probably just going to get some used, old Toyota truck. It's not like I want to ride in your smelly truck anyway. . . . Mom, are you coming?"

"I'm thinking about it," she said and rolled her eyes at them.

The night before, the kids gathered on their parents' bed, sitting close to their mom and chatting.

A couple of days later, Rich reminded Carolynne of that moment when she began to cry looking at photographs from the start of their relationship. She talks often about how she was prettier then. Sometimes, she said, she's overwhelmed by not being the wife and mother that she wants to be.

"I just don't feel as valuable," she said.

"There's still lots of value, Carolynne," Rich told her. "Every day you're home, every day you're with EJ, every night you read to him. . . . There's still a lot of meaning."

Rich has been collecting video and photos on his cell phone. He wants the kids to have all of the things he didn't have. He's encouraged Carolynne to write letters to them, but the idea is daunting.

"I feel like I'm saying goodbye," she said, "and I feel like I have to be psychologically ready to do it."

Rich said Carolynne has the chance to leave them words that will last into the future - advice for their first day of college or their wedding days. To her, the message will be simpler.

"I want them to know beyond a shadow of a doubt that there's no question that I love you and that I tried - we tried," she said.

"They'll see that," Rich said softly, rubbing her hand in his. "They'll see that, darlin'."

Exhaustion . . . and goals

By mid-September, Rich looked haggard and Carolynne's spirits were low. A CT scan had shown an abscess of fluid in her liver, and Carolynne had gone to the Lahey Clinic to have a tube installed to drain what doctors thought was an infection. She had to leave it in for more than a week.

At home, EJ climbed the rungs of the kitchen chair she sat in and into her lap. She pressed her palm against his back to keep him from leaning against the drain.

"I'm constantly having to protect myself when he's home," she said.

The same week, the woman who drove EJ to and from day care had to stop. Rich had been doing more running around than usual. Both felt low on energy.

"It's bad when we decay at the same time," she said.

Rich left for a two-night business trip. The next morning, Carolynne was carrying EJ down the stairs on her back when she fell. He was okay, but she hit her chest. The fall didn't damage the drain, but she'd later learn she had broken her sternum.

Then Carolynne received news from Jenkins that the abscess was likely caused by cancer blocking her intestines and she needed a stent put in to open it up. But the radiologist could find no blockage there. That was good news, so long as Carolynne's body could heal the abscess on its own.

The next day, Carolynne looked weaker than usual and was fatigued. She said she was anxious to get back to treatment. She had been almost a month and a half without it.

"It's not fun," she said. "But, I want to get to my goals."

Rich and she talked about how they hadn't found time yet to put videos together. "The days just disappear," he said.

They talked about collecting stories about Carolynne from family and friends, too. Maybe people would share them at her funeral if a camera were set up there, he said.

"And you can put a sign by it: 'Messages to the kids,'" she said.

Last week, Carolynne's liver function had worsened. Blood work showed increases in ammonia, which causes disorientation. She'd forget what she had done from day to day. Pain in her shoulder had intensified and spread to her lower back, and she was sleeping more than usual.

Six months since they returned to Brooklyn, the St. Pierres still don't know how much of their bills insurance will cover. In August, Rich sold land he had been hoping to build on to help pay some costs. But if insurance doesn't help with a large percentage of the bills, the family will have thousands of dollars of debt.

Yet, always, between the worried looks Rich gives his wife each morning, watching for further yellowing around her eyes, there are good moments. Last Saturday, Carolynne sat outside in the sun while EJ ran around the yard and Melissa and Brian raked the leaves.

"We're still living," Rich said.

On Wednesday, about seven weeks since Carolynne's last treatment, he woke up early and worked on the computer. Then he and Carolynne got in the car, dropped EJ at day care and got on the road, bound for Connecticut and another dose of chemotherapy.



Carolynne sits in bed with EJ before reading him to sleep. Every night that Carolynne is around to read to EJ "counts for everything," Rich said.